
Underreporting of Minority AIDS Deaths in San Francisco Bay Area, 1985–86

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Synopsis

A disproportionately high number of AIDS cases in the United States involve members of racial minorities.

SURVEILLANCE DATA from the Centers for Disease Control (CDC) reveal that AIDS patients in the United States are disproportionately Hispanic and black (1, 2). By 1989, 27 percent of all persons with AIDS were black, and 16 percent were Hispanic, whereas blacks constitute 12 percent of the total U.S. population and Hispanics 6 percent (3). In California, where 25 percent of the population is Hispanic and 8 percent is black, 13 percent of people with AIDS were classified as Hispanic and 12 percent as black in 1989 (4, 5). The incidence rate of new AIDS cases among Hispanics and blacks in California, however, rose faster than among whites during the last year.

Knowledge about epidemiologic trends among racial or ethnic minorities is used in determining the alloca-

Even so, AIDS deaths of minority members may be undercounted.

The completeness of reporting of AIDS deaths to the California AIDS Registry (ARS) among Hispanics, blacks, and whites in 1985 and 1986 from the San Francisco Bay Area was investigated. Death certificates listing AIDS as a cause of death or associated condition were identified and cross-checked with cases reported to ARS, current to December 1988. Death certificates were checked by hand for racial or ethnic classification using a definition of Hispanic based on information available on certificates. Three causes of undercounting in ARS were identified: a death was not reported as an AIDS case at all, an AIDS case was reported to ARS but the person was listed as still living, or an AIDS death was reported to ARS with a different racial or ethnic classification.

The proportion of cases not reported at all was similar for all three racial-ethnic groups (5–8 percent). The proportion of deaths reported for persons listed in the registry as still living was 12 percent for Hispanics and 9 percent for blacks, compared with 5 percent for whites. For Hispanics, under-counting was largely due to ethnic misclassification. Twenty percent of Hispanics had been counted as white in the AIDS registry. In comparison, 4 percent of blacks and 1 percent of whites were misclassified by race. AIDS deaths among blacks and Hispanics may be undercounted, even in an area with good AIDS surveillance systems. This suggests that overrepresentation of minorities among AIDS cases in the United States may be even greater than indicated by current reporting data.

tion of public funds for social and health care needs and is highly dependent on surveillance data and the accurate reporting of cases. Evaluation of the completeness of AIDS reporting has been performed in several cities by checking AIDS cases using death certificate searches and active hospital surveillance. These studies show case reporting to be 83–100 percent complete (6–8). A recent report from South Carolina comparing hospital discharge records with reported AIDS cases revealed that case reporting for blacks was 53 percent compared to 71 percent for whites (9). Few other studies, however, have determined whether surveillance methods may capture AIDS cases among minorities less thoroughly.

We looked specifically at the completeness of AIDS

reporting for blacks and Hispanics compared with whites in five San Francisco Bay Area counties by comparing death certificates with State AIDS registry data. This study examines whether AIDS deaths among minorities are less well-reported than among whites, and the degree to which this may be due to racial or ethnic misclassification.

Methods

Death certificates for 1985 and 1986 were obtained from the California Department of Health Services for the five San Francisco Bay Area counties (San Francisco, Alameda, Contra Costa, San Mateo, Marin). Certificates were reported by the county of residence at the time of death. Death certificates were then selected according to International Classification of Diseases, Ninth Revision (ICD-9) codes of AIDS-related diagnoses listed as underlying causes of death. These codes encompass various known AIDS-related conditions, and similar lists have been used elsewhere to perform death certificate searches (7-9). Codes used in this study included immunodeficiency (279.1, 279.3), *Pneumocystis carinii* pneumonia (136.3), Kaposi's sarcoma (173.9), candidiasis (112), cryptococcus (117, 321), cytomegalovirus (078.5), herpes simplex (054), meningitis-unspecified viral, ages 20-50 (047.9), mycobacteria, atypical and other (031, 032), *Mycobacterium tuberculosis* (011), non-Hodgkin's lymphoma (200.2, 202.8, 200, 200.1), pneumonia-unspecified, ages 20-50 (486.0, 480.9), progressive multifocal leucoencephalopathy (046.3), toxoplasmosis (130), histoplasmosis (115), viral encephalitis (49), and other infectious diseases (003, 007, 008, 009, 013, 018). Death tapes were screened initially for underlying cause of death. The death certificates were then pulled and reviewed by hand, and only those for which AIDS was specifically written as an underlying cause of death, or as an associated condition, were used in this analysis.

Death certificates were also selected according to race or ethnicity marked as Hispanic, white, or black. The racial or ethnic classification of persons listed as white or Hispanic was then re-evaluated. The ideal definition of Hispanic or Latino is controversial (10, 11). We were forced in this study to employ a definition based on the information available on California death certificates. Hispanics were considered to be those persons who on the death tapes were designated as of known Hispanic origin (coded as Mexican, Mexican American, Puerto Rican, Cuban, Central or South American, or other Spanish or Hispanic); also considered were those listed as of unknown Hispanic origin or as white, non-Hispanic, but who had Hispanic surnames and whose parents had Hispanic surnames. For a

case to be reclassified by us as that of an Hispanic, the decedent and parents all had to be born within the United States or Latin America. Blacks were classified according to the racial identification marked on the death certificate, since there was no corresponding means by which to re-evaluate their classification.

A total of 1,476 death records were selected on ICD-9 codes and race or ethnicity marked as black, Hispanic, or white, and subsequently reviewed by hand. Of these, 1,273 had AIDS written on the death certificate as an underlying cause or associated condition. Only 15 persons listed as white, non-Hispanic and 11 listed as of unknown Hispanic origin on the death certificates were reclassified as Hispanic using our criteria.

The California AIDS registry (ARS), the State component of the CDC AIDS reporting system, collects all AIDS case reports from California counties and is updated several times each month. AIDS cases during the period 1985-86 were classified according to the patient's county of residence at onset of symptoms (changed as of July 1989 to county of residence at time of diagnosis). In California, names are reported for approximately 40 percent of cases in ARS files. Therefore, cases from death certificates were cross-checked with cases in the ARS using the following steps and compared by exact name when available. Soundex is a coding system used to protect confidentiality, based on the first letter and consonants of the last name (12). The proportion of cases linked to ARS files at each step is in parentheses.

1. Cases were first matched by Soundex, sex, date of birth, and date of death (79 percent), and without date of death (6 percent).
2. Next, unlinked deaths were matched by Soundex code only (5 percent).
3. Finally, matching was performed by date of death or date of birth only (2 percent).

All matches that were identified during steps 2 and 3 were checked manually, revealing matches with minor discrepancies in the spelling of surnames or reported dates. This left 8 percent, or 102 deaths, not linked to a registry case.

Results

Overall, 1,273 AIDS deaths were identified among blacks, Hispanics, and whites from death certificates. Of these, 210 deaths were considered discordant with the AIDS registry (see table). Three causes of non-matching were identified: (a) the death was not reported to ARS as an AIDS case at all, (b) the case was reported to ARS but the person was listed as still living,

Results of matching AIDS deaths identified from death certificates with AIDS cases from the California AIDS Registry (ARS), San Francisco Bay area, 1985–86

Death certificate cases	Discordant cases									
	Number	Not listed in ARS			Listed in ARS still living		Discordant race or ethnicity		Total	
		Number	Percent	Percent	Number	Percent	Number	Percent	Number	Percent
Blacks, total	106	8	8	9	9	4	4	21	20	
1985	38	2	5	2	5	3	8	7	18	
1986	68	6	9	7	10	1	2	14	21	
Hispanics, total	119	6	5	114	12	124	20	142	35	
1985	49	1	2	14	8	17	14	111	22	
1986	70	5	7	110	14	117	24	131	44	
Whites, total	1,048	88	8	51	5	8	1	147	14	
1985	400	39	10	6	2	4	1	49	12	
1986	648	49	8	45	7	4	1	98	15	
Total	1,273	2102	8	74	6	36	3	210	17	

¹12 Hispanic deaths were both listed in ARS as still living and misclassified as white. They are counted only once in the total column.

²Includes at least 8 cases not meeting the CDC AIDS case definition and at least

10 cases initially diagnosed outside California.

NOTE: Percents refer to proportion of cases among those identified from death certificates.

or (c) the case was reported to ARS with a different racial or ethnic classification.

The proportion of deaths not reported to ARS at all was approximately the same for all three groups (5–8 percent). Among Hispanics, however, 20 percent of all AIDS deaths were misclassified as white in the registry, and among blacks, 4 percent were misclassified as white (see figure). Among whites, on the other hand, only 1 percent were misclassified as either black or Hispanic in ARS. The proportion of persons listed as still living by the registry was the greatest for Hispanics at 12 percent, compared with 9 percent for blacks, and 5 percent for whites.

Cases were also evaluated separately for each year (see table). The total proportion of discordant cases for all three racial categories was greater in 1986 than 1985, and the greatest difference was among Hispanics, with an increase in discordant racial classification from 14 to 24 percent. For all three racial or ethnic groups, failure to report the deaths of persons with AIDS to the registry was also greater in 1986, which may be partly attributable to the lag time in the reporting of more recent deaths.

Discussion

The data reveal that the proportion of deaths not reported to ARS at all was approximately the same for all three groups at 5 to 8 percent. A failure to update cases as deaths, or to classify deaths in the proper racial or ethnic category, however, was higher for blacks and Hispanics than for whites and may lead to an undercounting of AIDS deaths for these groups, even in an area with a good surveillance and reporting system.

This study does not attempt to address the general problem of underreporting of AIDS cases (rather than deaths), although our findings regarding misclassification would also apply to people reported to have AIDS who are still living.

The problem of undercounting of deaths is greatest here for Hispanics and appears to be due largely to misclassification as white in the ARS. We feel that death certificates may be more reliable than ARS reporting forms in determining the correct racial or ethnic classification. The classification scheme for Hispanic on death certificates is detailed and includes seven different Hispanic origin categories. It is usually filled out by the funeral director or hospital vital statistics staff with information obtained from the next of kin. In contrast, AIDS case reports provided to ARS are most often completed by physicians who determine the racial or ethnic category, and who may do so without inquiring about the patient's or decedent's background. In addition, there is only one Hispanic origin category on the form.

There was also a high concordance between the classification marked on the death certificates and ethnic classification under our operational definition. Review of cases listed as Hispanic on death certificates revealed that all of these were consistent with our definition of Hispanic using surnames, and birthplace of decedent and parents. In addition, there were 15 deaths among white non-Hispanics and 11 deaths among those of unknown Hispanic origin on death certificates whom we reclassified as Hispanic based on information about the decedent and parents. Of these, 16 were considered Hispanic in ARS. Therefore, our reclassification accounted for 10 of the 24 Hispanic persons listed as

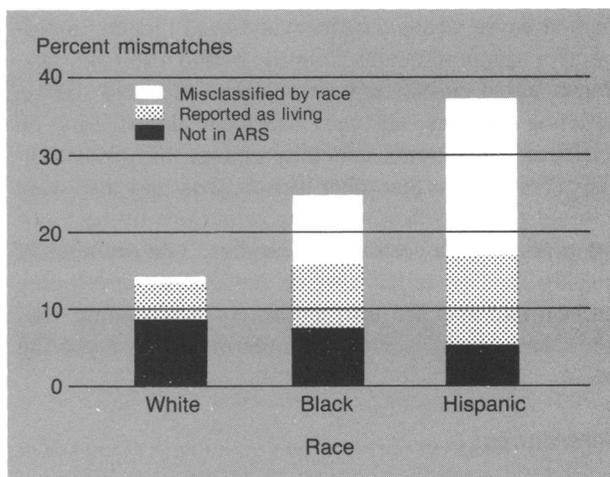
white in ARS. When the counties were notified by the State of the misclassification of ethnicity in ARS, the local jurisdictions agreed to change 5 of these 10 cases based on further investigation. All 14 persons who were classified on death tapes as Hispanic of known origin but who were listed as white in ARS were changed by local jurisdictions to Hispanic. In summary, of the 24 total Hispanic cases we considered misclassified in ARS, 19 were subsequently changed by the reporting counties.

We are aware that the definition of Hispanic or Latino is a matter of controversy. Nevertheless, we needed to employ an operational definition based on available information. The classification scheme we used required information on surnames and places of birth and the evaluation of the death certificates themselves, rather than the death tapes. Also, it could not include those who may have been self-identified as Hispanic but who were of mixed parentage, or who did not have clearly Hispanic surnames. For future studies of undercounting, use of the Hispanic classification as marked on death certificates may be adequate.

For blacks, racial misclassification was not as great a problem. The proportion of discordant cases was higher than for whites (20 percent to 14 percent), but this was primarily due to cases in which the person was listed as still living. For both blacks (9 percent) and Hispanics (12 percent), the proportion of people listed as still living was greater than among whites (5 percent). The reason for this less complete updating of the vital status among blacks and Hispanics is not clear and merits further evaluation, particularly as these statistics could affect reported AIDS survival data among minorities. A possible explanation is that followup medical care for minorities may not be as complete.

Although death certificates are useful in finding unreported AIDS cases, the ICD-9 codes that we used for screening were not all-inclusive and may not have identified all AIDS-related mortality. We did not, for example, screen certificates listing suicide or intravenous drug use as causes of death (13, 14). In addition, we could only screen ICD-9 codes for underlying causes of death. This procedure would not have picked up cases which listed AIDS, and AIDS-related diagnoses only as associated conditions. Other cases were not included because AIDS was not specifically written on the death certificate, even though the diagnosis was highly likely given the demographic information and the associated causes of death. In 1985, for all three ethnic or racial groups, 154 deaths not found by death certificate searches were reported to ARS from the five San Francisco Bay area counties. A total of 641 deaths for 1985 and 1986 were thus reported to ARS or listed on death certificates or both. Therefore, our death certificate

Proportion of AIDS deaths found through death certificates, not matched to the California AIDS registry (ARS), among whites, blacks, and Hispanics, San Francisco Bay Area, 1985-86



search could not pick up 154, or 24 percent, of these due to the reasons previously listed. Values were slightly lower for blacks and Hispanics (21 percent) than for whites (25 percent).

The 102 deaths listed in the table as not recorded at all in the registry should be evaluated taking the following into consideration: These cases were cross-checked in supplemental files at the State Office of AIDS, which contain cases that are reported but do not meet the CDC case definition, and cases that should be reported outside California. Eight deaths listed as due to AIDS according to the death certificates were identified in supplemental files but were found not to meet the CDC AIDS case definition, and 10 additional deaths were among cases with initial onset of symptoms outside California. Therefore, these cases could not be listed in the registry. These 18 deaths, which were all among whites, are still included among the 102 cases in the table. They were not removed from analysis as supplemental files are known to be incomplete.

The selective underreporting of minority AIDS deaths that we found suggests that the overrepresentation of minorities among AIDS cases in the United States may be greater than indicated by official statistics. The table indicates that 20 percent of Hispanics, 4 percent of blacks, and 1 percent of whites were reported to ARS but listed with a different racial or ethnic classification. If these values are used to correct current California statistics, the proportion of cases would increase from 12.8 percent to 16 percent among Hispanics, 11.6 percent to 12 percent among blacks, and decrease from 73.7 percent to 70 percent among whites (4, 5). Such changes may have important implications for predicting epidemiologic trends accurately and targeting public health interventions.

The California Office of AIDS is currently performing death certificate searches on a monthly basis, including a review of racial or ethnic classification as marked on the death certificate and has initiated a retrospective search of deaths from the period 1980–87. Discrepancies in classification are sent to the field staff in reporting counties, and they reevaluate information on decedent and parents and may change the classifications. We suggest that other jurisdictions may also want to evaluate AIDS deaths among minorities by performing similar death certificate searches. The problem of misclassification might also be reduced by developing uniform and specific instructions for determining Hispanic status to all persons completing AIDS reporting forms.

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Comparison of Risk Factors for Ill Health in a Sample of Homeless and Nonhomeless Poor

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Synopsis

This cross-sectional survey was undertaken to examine whether the homeless poor have a higher prevalence of risk factors for ill health than the nonhomeless poor. Seventy-one adults in four age groups who attended a free-meal program in northern California were recruited during a 1-month period in 1987. The majority of the respondents lived on the streets, in vehicles, or in substandard housing located in an area

undergoing rapid urban redevelopment. Regardless of employment or government assistance, the income of 100 percent of the respondents fell below the Federal poverty level.

Overall, the sociodemographic profile of the study population was remarkably similar to that of the general population of California adults. Sixty-six percent had completed high school, 78 percent had lived in the city for 5 or more years and, at most, 23 percent reported serious alcohol or emotional problems. When compared with the nonhomeless poor, the homeless poor were slightly less educated, more mobile, and more likely to report alcohol and emotional problems.

Larger differences were evident for health-related variables, with the homeless poor being significantly less likely to have health insurance coverage, to receive preventive health care, and to be nonsmokers than the nonhomeless poor (P values <.05). There were also large differences in access to heated rooms, running hot water, and cooking facilities, with approximately 90 percent of the homeless poor reporting no access to these fundamental necessities.